S. 9

Fax

To: CHARLES CASIMATY
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From: TAMARA LOWE
Fax:
Phone: 0405 700 231

Date:
Subject: Investigation into the renewal of the Disabilities Services act
Comments:

The Media Release is about my Petition I did and Sue Napier Presented it in Parliment for me. thaught this may have also been of interest with my Submission

right now
There's a better way

media release
Tasmanian Liberals

Sue Napier MP
Tasmanian Liberal Member for Bass
Wednesday 29 April, 2009

1286 people petition for more respite care for children with a disability

Tasmanian Liberal Member for Bass, Sue Napier, today presented a petition to Parliament signed by 1268 people, predominantly from the North of the State which calls for the State Government to "address the gross neglect in the failure to provide adequate respite care for children and young adults."

The petition goes on to call for "adequate funding to be made available to correct the serious lack of respite including the provision of beds and carers for the families in our community living with disabilities".

Respite is urgently required for children in the age range of 0-5 as currently none exists, as well as an increase of the appropriate respite for ages 5-17 and 17 and above.

Mrs Napier said that people who signed the petition were from Scottsdale, Bridport, Pioneer, most Launceston suburbs, Lilydale, Legana, Derby, George Town, Herrick, Branxholm, Weldborough, Gravelly Beach, Swan Point, Evandale and even more areas.

"Clearly the lack of access to respite is being felt by many families," Mrs Napier said.

"Whilst St Giles has two houses which can cater for between 6-8 children aged 5-17 years old, demand clearly outstrips supply. 1286 people are willing to sign their name to a petition calling for more respite services to be available, and urgently.

"There is no respite services for 0-5 year olds currently.

Even though we don't have institutions for children with disabilities anymore our children still suffer from damage, abuse and misunderstandings of their disabilities. We have become not just parents, but their carer, advocate, provider, teacher, social worker and friend. Now parents have carer allowances and a lot of responsibilities (if not all in some cases) have been given pack to the family and the burden is immense. We have to try and help our children with all their needs and requirements whilst still looking after the family and perhaps trying to hold down a job as well. Our own homes have become the institution, or can feel like an institution for us as it can be like a life sentence, trapped in the home where the child or children feel safe and calm. There are no friends for us or the person with the disability and we feel distanced and cut off from the world. Leaving the house is a major expedition, filled with difficulty and the urgent need to return home as quickly as possible. Enjoyment and fun often aren't possible or a factor of an outing. The child's disability affects every aspect of their lives and the carer's everyday and impacts on all situations and circumstances that may arise. Other people and run of the mill kids don't want to know and hide their heads in the sand, and treat you and your children like lepers. This is the case not just for the disabled child but for the parents and carers who look after them.

Equal Rights

- Public ignorance: need to build upon knowledge of disabilities
- Schooling for children with disabilities should be appropriate and supportive with the use of teachers' aides. Aides are not recognised enough in their roles as a teacher. Aides time should be decided by the school, which has in-depth knowledge of the child, and not a government department which doesn't know them
- High School Support: there ~~are~~ is currently no appropriate assistance ~~[illegible]~~ once primary school is finished- no buddies anymore and older children are very cruel
- Giant Steps is the only Autism specialist school in Tasmania, and needs to be able to expand to accommodate the needs of the children and larger numbers so they are able to learn to the absolute best of their abilities
- Money needed for ramps for disability access into buildings- maybe we should do away with stairs and just have ramps
- Quality of life- the need for meaningful things to do at different ages, such as pre-school, early intervention, adult programs, work and leisure programs. Parents and carers have the right for opportunities to enjoy leisure and personal time just as much as the person with the disability- if we can't take care of ourselves how can we continue to care for our children? Marriage breakdowns are common due to such pressure on the relationship- there is little or no time for you and your partner.

Service Provision

- Emergency Care: for situations such as funerals where taking the child with the disability causes more anxiety, grief and stress upon the carer and others than needs to be. An overnight or day care facility to cater fro such needs would make things much easier for all concerned, and mean that the parent or carer would not have to take the child with them (as I had to in the case of my own brother's funeral in Hobart when I live in Launceston). This care needs to cover children of all ages, especially before school age.

- Transport to school or work when carer is unable to do this
- Holiday care: again there is a great need for pre-school placements and assistance for holiday programs and respite care.
- There is also a need for organised outings and worthwhile leisure activities with trained carers and aides for all ages of children, especially over the long school holidays at Christmas. There are some services available, however when the person turns eighteen most services stop, while the young person would still love and enjoy taking part in the activities and outings in their young mind, How do you tell them that they can't go anymore?
- For the profoundly disabled child there aren't services available because they need individual attention. Therefore the leisure and holiday activities become the responsibility of the parents and carers all over again.

Respire Care

- As the carer ages and becomes more frail, and may even need hospitalisation themselves, the adult respite care facilities become full of people with disabilities who cannot go home. More respite care houses, beds and carers are desperately needed for all ages of children and adults. This is particularly important for ages 0-5 as a disabled baby or toddler can be a large and tiring responsibility and none currently exists in this age group

Health/Hospital Care

- We need an advocate or person with the knowledge of the disability to liaise with parents and staff at the hospital for the care of these special children. An aide for hospital care to help look after the child/adult so that the parent can look after their other children and themselves and take a break in the case of a long stay especially
- Both Jake (a friend's child) and Jason (my son) have had traumatic stays in hospital recently due to issues with staff treatment (Jake's leg was broken) and the capability of hospital staff to manage the children's needs.

Support (Home and Community)

- There needs to be another adult (carer/aide) to assist with feeding, bathing and other routines for children with disabilities so that the primary carer can attend to other members of the family and responsibilities. Someone to accompany the family on outings and holidays is also important so that they can have some individual enjoyment and one on one time for personal relationships

Health Issues and Foods

- The cost of feeding a disabled person with special eating habits or allergies is phenomenal- about $30 to $100 over the budget for a normal household for one disabled person
- The incontinence allowance isn't enough to cover needs- many children need nappies - at least at night - for their whole life. Pull ups especially $13 for 9 at 3-4 a day- one larger one at night

Aides or Carers

- Some of these people sometimes can be unable to help care for special people with disabilities due to their lack of knowledge or training and ability. They may mean well, however they may need to have work experience and also have had personal experience with this problem to help them to decide if they can cope or have the ability to work with these clients
- A lot of the burden is put on grandparents for respite, for those that will accept it (my own don't want to help of have anything to do with my children), due to a myriad of behavioural and intellectual care issues that us as parents and carers have to deal with on a daily basis. These include sexual and hormone issues (such as menstrual problems with girls), and issues that the everyday person would never imagine or think about
- Sometimes parents and carers are put in a situation where they have no other option but to leave their disabled children with relevant authorities because of the build up of stress and pressure and not being able to get any respite or help
- Some parents and carers even consider (or actually do) take their own life and the child's rather than living the life we have to or having to worry about how our children are going to cope or be managed without us when we are gone, as my friend has shared with me and others that have already done so. This is sad and should be avoidable.

I have had personal experience of many of the issues outlined in this submission and very close involvement in others within the disability circle. I have a myriad of ideas and knowledge on how things could be done better in the disability sector and feel that I am more than able with my knowledge and experience to make a very valuable contribution.

LIBERAL

The Tasmanian Liberals: News

Date : Wednesday, 29 April 2009

Subject : **1286 PEOPLE PETITION FOR MORE RESPITE CARE FOR CHILDREN WITH A DISABILITY**

Author : Hon Sue Napier MP

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"Clearly the lack of access to respite is being felt by many families," Mrs Napier said.

"Whilst St Giles has two houses which can cater for between 6-8 children aged 5-17 years old, demand clearly outstrips supply. 1286 people are willing to sign their name to a petition calling for more respite services to be available, and urgently.

"There is no respite services for 0-5 year olds currently.

"Discussions with the sector have suggested that the focus with younger children and the 5-17 year old group should be on intensive family support, but families are also asking for support to give them and the other siblings a break from the 24 hour task of caring for their children.

"The Tasmanian Liberals have also received many reports that the South has a shortage of respite care too.

"Whilst the State Government might argue that the new Gateway project will hopefully be able to help parents and their children with a disability, disability support under the Gateway project will not be available for at least 12 months.

"The sector also fears that there will be no extra funding available to fund services such as respite and family relationship support.

"Clearly petitioners are of the view that this area has been neglected, and that the need is urgent.

"How many families and their children will end up under duress and in need whilst waiting for services? This petition demands the State Government address this issue urgently."